Arkansas Spinal Cord Commission

2009 Annual Report

Mike Beebe, Governor

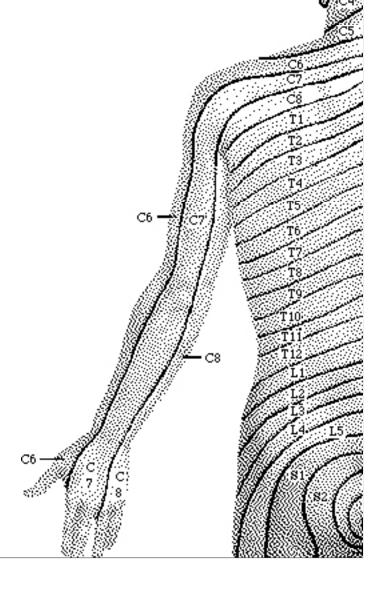
Arkansas Spinal Cord Commission

Jimmy Ashley, Jonesboro, Chair Mike Cranford, Foreman Sandra Turner, Little Rock Jon Wilkerson, Center Ridge John Wyrick, Mabelvale

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AGENCY HISTORY AND DIRECTION

Agency Mission

The mission of the Arkansas Spinal Cord Commission is to administer a statewide program to identify and meet the unique and lifelong needs of people with spinal cord disabilities in the state.

Scope of Services

Each year, nearly 200 Arkansans sustain spinal cord disabilities that are severe enough to limit their abilities to function in their homes, their jobs and their communities. For most of these individuals, the disability is permanent, causing limitations in their mobility, sensation and other functional abilities. These disabilities have a significant impact on the individuals and their families and communities.

The Arkansas Spinal Cord Commission provides a variety of services to individuals with spinal cord disabilities and their families throughout the state of Arkansas. Fifteen Case Managers in 10 field offices provide services to citizens in all 75 counties. Services are tailored to the needs of the individual and family and are as diverse in scope as the families that we serve. The Commission staff work in concert with state and federal agencies, medical and home health services, rehabilitation and educational institutions and



community agencies to assist these individuals in accessing the services that they need. In addition, the Commission conducts educational programs and disseminates educational materials on spinal cord disabilities to help individuals, families and healthcare professionals understand the unique medical conditions and complications resulting from spinal cord disabilities.

The Arkansas Legislature established the Commission in 1975 to provide a coordinated approach to early identification, emergency care, acute and rehabilitation treatment and long term follow up. Within this system of care, the Commission provides a link between Arkansans with spinal cord disabilities and their families and the multifaceted system of treatment and services available to them.

It is the goal of the Arkansas Spinal Cord Commission to ensure that all persons with spinal cord disabilities in our state are provided every opportunity to live as independently and productively as possible.

Legislative Mandates

ACT 311 of 1975 (ACA 20-8-201)

"An act to establish a program for the quality care, treatment and rehabilitation of persons who have sustained acquired or congenital spinal cord injury or damage: To establish a state Spinal Cord Commission to administer said program: to authorize the cooperative development of an Arkansas Spinal Treatment Center and for other purposes...."

ACT 330 of 1977 (ACA 20-8-206)

"... The Arkansas Spinal Cord Commission shall establish and maintain a central registry of spinal cord disabled persons: Every public and private health and social agency and attending physician shall report to the Commission within five (5) calendar days of identification of any spinal cord disabled person. Consent of the individual shall be obtained and the report shall contain the name, age, residence and type of disability and other information as needed.

Within fifteen (15) days of the report, the Commission shall notify the individual or family of their right to assistance, services available and eligibility requirements and make referrals to the appropriate agencies and services to assure optimal rehabilitative services."

PROGRAM SERVICES

Case Management Services

Coping with a spinal cord disability is difficult. The newly injured individual and his family face a plethora of questions and concerns about the disability and how it will affect their future.

The Case Manager can answer many questions regarding the injury and its effects for the individual and his family. Case Managers also assist families in identifying and applying for services to assure that they access every available resource. As the individual progresses through treatment, the Case Manager provides an integral role in assuring that the individual's transition home is a smooth one.

The Case Manager is also there for those individuals living in the community who need information, referral and assistance with obtaining treatment or equipment. This community based intervention prevents costly stays in hospitals and institutions of these otherwise independent individuals.

In Fiscal Year 2009, 2,533 Arkansans with spinal cord disabilities received services from ASCC. Fifteen Case Managers made 6,031 visits to these individuals, providing services to meet their unique needs.

Long Term Attendant Care

Spinal cord injured Arkansans with quadriplegia depend on someone else to feed them, brush their teeth, get out of bed and get dressed each day. For those eligible spinal cord injured quadriplegics, ASCC provides a long term attendant care program allowing individuals to remain in the community with the assistance of a personal care provider who assists them with their basic needs for up to four hours a day. Designed to keep individuals out of nursing homes, this small but cost effective program served 24 clients in fiscal year 2009 at an average cost of \$8,663 per person.

Spinal Cord Disability Education

An ASCC priority in fiscal year 2009 was spinal cord disability education. Recent research results reported in the *Journal of Spinal Cord Medicine* state that individuals with spinal cord injuries (SCI) prefer to receive SCI information from experts followed by the Internet. The Commission provided expert information to our clients, families, health care professionals and

general public through several projects.

The first project was a revision of "new referral" packets. ASCC staff provide these printed materials to newly injured individuals, families of newborns with spina bifida and persons diagnosed with spinal cord diseases at their initial visit and assessment for services. Staff evaluated the packets, researched the latest cutting-edge information, solicited information from the ASCC Medical Director and other health professionals and made recommendations for changes in packet content. This included purchasing new resources and rewriting others. With the dissemination of the new packets, our regional offices were also provided with the reference materials used to develop the packets.

The second educational project conducted two educational conferences. In August, *Living Well with Spinal Cord Injury* attracted over 250 clients, family members, and rehabilitation and health care providers to Pulaski Technical College in North Little Rock. The conference attracted national speakers and exhibitors from Massachusetts, New Jersey and Maryland. The keynote speaker was Joseph Canose from the Christopher Reeve Paralysis Foundation. Other sessions included sexuality, advocacy, spinal deformities and a "living well" panel of experts. Cosponsors, lead by the Stephens Spine Center at UAMS, funded the conference along with exhibitors and registrations. In October, *Spina Bifida Fall Family*

Fest, was an educational day aimed at individuals living with spina bifida and their families. Educational sessions, featuring national and regional experts, included fitness, advocacy, transition and driving were coupled with seasonal recreation activities and daycare for children attending the event. This was a collaborative event with the Spina Bifida Support Group of Arkansas who provided funding and ASCC who planned and conducted the event.

Thirdly, the ASCC website was revised. Using client survey results as well as data on national trends, website content was revised or updated, with the entire website redesigned for accessibility. Also, a message board was added to allow individuals to post information, questions and resources.

Providing well-documented, quality information on spinal cord disabilities is a priority of the Commisssion. It is essential that clients be able to rely on the information provided by our Case Managers as well as our online and print resources.



SPINAL TREATMENT SERVICES

AGENCY BUDGET



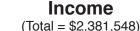
Spinal Treatment Services

Imagine you or a family member has sustained a spinal cord injury. The results are devastating, affecting every aspect of the family's life and livelihood. In the midst of dealing with the physical and emotional aspects of the injury, reality strikes: Where and how will we get the needed wheelchair to allow him to be mobile? How will we get the wheelchair into our house?

Spinal cord injury is a catastrophic and costly disability, taking it's toll both personally and financially. Cost of spinal cord injury over a lifetime averages over one million dollars. Each year, individuals with spinal cord disabilities face health care costs averaging \$35,000 more than other citizens. These costs have more than doubled since 1999. ASCC provides needed assistance to meet these costs for individuals with spinal cord disabilities who meet established medical and financial criteria. These purchases are authorized by the ASCC Case Managers only when similar benefits, such as insurance coverage, have been exhausted.

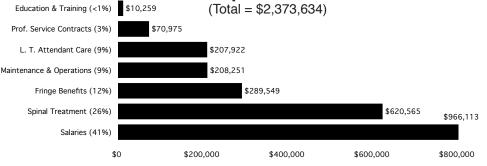
These purchases include medically prescribed equipment such as wheel-chairs, braces, therapeutic cushions, medical supplies and medications. In addition, the Commission assists with providing home modifications including ramping, driving adaptions and outpatient clinic and therapy visits.

In Fiscal Year 2009, the Commission expended \$620,565 for these essential goods and services. ASCC Case Managers leveraged an additional \$625,284 in goods and services on behalf of their clients. Though the number of clients on the ASCC registry increases slightly each year the number of clients who have unmet needs, little or no insurance coverage and who meet financial criteria continues to increase at a greater rate.





Expenditures





Spina Bifida Camp

 Wheelchair Ramps
 \$70,778

 Wheelchair Ramps
 \$72,265

 Orthotic/Prosthetic Aids
 \$175,531

 Wheelchairs
 \$225,064

 \$0
 \$50,000
 \$100,000
 \$150,000
 \$200,000

AGENCY REFERRAL SERVICES

FY2009 New Cases by Etiology

Traumatic (n=110)

Cause	Number	Percent
Motor vehicle	37	33.7%
Falls	25	22.7%
Gunshot	19	17.3%
Motorcycle	10	9.1%
Diving	4	3.6%
ATV	3	2.7%
Bicycle	2	1.8%
Falling object	1	0.9%
Equestrian	1	0.9%
Other, specified	8	7.3%

Non-traumatic (n=64)

Cause	Number	Percent
Spinal cord tumors	11	17.2%
Spina bifida	9	14.1%
Multiple sclerosis	8	12.5%
Spondylosis	8	12.5%
Hemorrhage / thrombosis	6	9.4%
Spinal abscess	4	6.3%
Transverse myelitis	2	3.1%
Amytophic lateral sclerosi	s 2	3.1%
Unknown	2	3.1%
Guillain-Barré	1	1.5%
Other diseases	11	17.2%

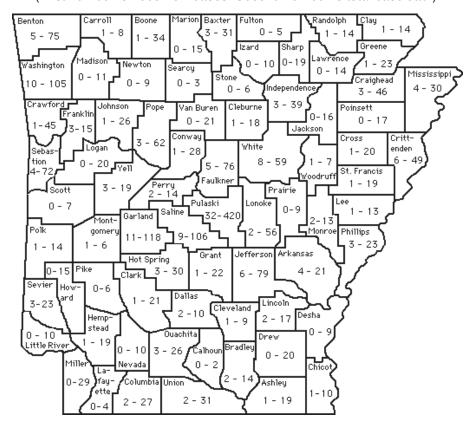
Causes of Spinal Cord Disabilities

Referrals to the Arkansas Spinal Cord Commission during FY2009 numbered 229; of these, 174 met the medical criteria and were accepted as new cases.

Compared to FY2008, the overall number of traumatic cases remained about the same although the percentage of gunshot, motorcycle cases and other, specified cases increased and the percentage of motor vehicle cases declined. The number of non-traumatic cases decreased 30.4% from the FY2008 level. Multiple sclerosis, spondylosis and spina bifida cases decreased while the number of spinal cord tumor cases increased. The "other diseases" category consisting of a variety of "rare" diseases and conditions which historically have not resulted in spina cord disability remains high.

FY2009 New Cases - Caseload by County of Residence

(First number is 2009 new cases. Second number is total caseload.)

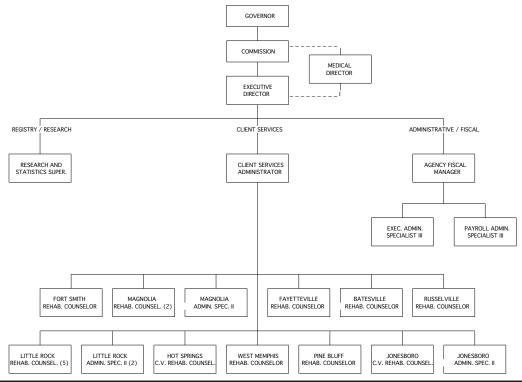


Arkansas Spinal Cord Disability Registry

The Arkansas Spinal Cord Commission maintains the oldest legislatively mandated spinal cord registry in the country. It is also one of the most comprehensive in the elements collected, as well as in the scope of spinal cord disabilities (including traumatic, disease and congenital cases). The intent of the Central Registry is to insure the referral of all persons with spinal cord disabilities in order that they obtain appropriate rehabilitative and other needed services.

In recent years, the Central Registry has also provided data to aid in the development of secondary condition prevention efforts and to identify factors influencing the independence of persons with spina bifida.

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